

# Caregiver Contribution to Self-care in Ostomy Patient Index: Turkish Validity and Reliability Study

Ostomi Hastasının Öz Bakımında Bakıcı Desteği İndeksi: Türkçe Geçerlik ve Güvenirlik Çalışması

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### ABSTRACT

Aim: This study was conducted to evaluate the Turkish validity and reliability of the Caregiver Contribution to Self-care in Ostomy Patient Index, to evaluate the relatives of patients with stoma who contributed to their self-care in Turkish society, and to contribute to the literature of the measurement tool.

**Materials and Methods:** This methodological type of research was carried out between September 2020 and January 2021 in a state and a university hospital in Tekirdağ. The research sample consisted of 223 individuals who contributed to the self-care of individuals with colostomy, ileostomy and urostomy, who applied for outpatient control. In the analysis of the data, descriptive statistics, language and content validity, confirmatory factor analysis (CFA), item analysis, internal consistency and test-retest methods were used.

**Results:** The Content Validity Index was 0.99 and Cronbach's alpha 0.890. According to the CFA, fit indices were within acceptable limits and all items were statistically significant in the 3 sub-dimensions of the scale. As in the original version of the scale, item 18, which was not statistically significant, was not included in the analysis and was accepted as an addition. The correlation between test-retest and scale items was 0.983 for the whole scale and between 0.973 and 0.987 for the sub-dimensions.

Conclusion: At the end of the study, it was determined that the scale was suitable for Turkish society and was valid and reliable in Turkish.

**Keywords:** Caregivers, ostomy, stoma, self-care, reliability, validity

#### ÖΖ

Amaç: Bu araştırma Ostomi Hastasının Öz Bakımında Bakıcı Desteği İndeksi'nin Türkçe geçerlik ve güvenirliğinin incelenerek Türk toplumunda stoması olan hastaların öz bakımlarına katkı sağlayan yakınlarının değerlendirilmesi ve ölçme aracının literatüre katkı sağlaması amacıyla yapıldı.

Gereç ve Yöntem: Metodolojik tipteki bu araştırma Eylül 2020-Ocak 2021 tarihleri arasında Tekirdağ'daki bir devlet ve bir üniversite hastanesinde gerçekleştirildi. Araştırmanın örneklemini polikliniklere kontrol için başvuran kolostomi, ileostomi ve ürostomili bireylerin öz bakımlarına katkıda bulunan 223 kişi oluşturdu. Verilerin analizinde betimleyici istatistikler, dil ve içerik geçerliliği, doğrulayıcı faktör analizi (DFA), madde analizi, iç tutarlılık ve test-tekrar test yöntemleri kullanıldı.

**Bulgular:** İçerik Geçerlilik İndeksi 0,99 ve Cronbach alfa 0,890 idi. DFA'ya göre ölçeğin 3 alt boyutunda uyum indeksleri kabul edilebilir sınırlar içerisinde olup tüm maddeler istatistiksel olarak anlamlı bulundu. Ölçeğin orijinal versiyonunda olduğu gibi istatistiksel olarak anlamlı olmayan 18. madde analize dahil edilmedi ve ek olarak kabul edildi. Test-tekrar test ile ölçek maddeleri arasındaki korelasyon ölçeğin tamamı için 0,983, alt boyutları için ise 0,973 ile 0,987 arasında bulundu.

Sonuç: Araştırma sonunda ölçeğin Türk toplumuna uygun olduğu ve Türkçe ölçek olarak da geçerli ve güvenilir olduğu belirlendi.

Anahtar Kelimeler: Bakım veren, ostomi, stoma, özbakım, güvenirlik, geçerlik

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## INTRODUCTION

A stoma is the opening that is most often created due to cancer and connects an organ to the skin<sup>1</sup>. Colostomy, ileostomy, and urostomy are the most common types of stoma, in which evacuation is provided by this surgical way to the abdominal wall<sup>2,3</sup>.

The stoma has a negative impact on the quality of life by changing the daily life activities, body image and interpersonal relationships of the individual. As a result of this effect, new social, economic, emotional, and physiological priorities may emerge for the individual<sup>4</sup>. As a result of studies, it has been reported that the daily activities of individuals with stoma are limited by approximately 3.46 times and that approximately 30–60% of individuals with stoma experience complications in and around the stoma after surgery. The training and counseling of nurses play an important role in helping individuals cope with these problems that reduce their quality of life, adapt to the stoma, and gain self-care skills<sup>5</sup>. In addition, attention is drawn to the importance of social support resources, especially family members, in adapting the individual to a challenging new lifestyle<sup>6</sup>.

Although self-care skills are carried out by the patient, as the word means, individuals often need the contributions of their families and relatives in this regard<sup>7</sup>. Families take an active role in giving advice on self-care skills of individuals with a stoma, making new decisions about the individual's health status and helping them to cope with their negative feelings about this situation, helping them to fulfill their self-care skills, and performing these skills instead of the individual when necessary<sup>6,8</sup>. Contribution to self-care can be determined by using valid and reliable tools in the evaluation of families and relatives who play an active role in the care of individuals with a stoma, and supportive training can be planned when necessary. Thus, a positive effect can be achieved in the adaptation process and quality of life of individuals with a stoma<sup>6,7</sup>.

There is no valid and reliable scale for Turkish society in Turkish language to evaluate the relatives who participate in the care of individuals with a stoma and contribute to their self-care. As a result of this study, it is thought that this deficiency will be eliminated. The aim of this study, which was planned in methodological type, was to evaluate the Turkish validity and reliability of the "Caregiver Contribution to Self-care in Ostomy Patient Index" and to evaluate the families and relatives of patients with a stoma who contributed to their self-care in Turkish society.

# MATERIALS AND METHODS

The study was planned in methodological type for the purpose of psychometric evaluation of the instrument.

The study was carried out between September 2020 and January 2021 in the general surgery, gastroenterology surgery and urology outpatient clinics of a state and a university hospital in Tekirdağ province. In order to evaluate the validity and reliability of a scale in different languages and cultures, it is recommended that the sample size should be 5-10 times the number of scale items<sup>9</sup>. The scale in this study consists of 22 items. The research sample consisted of 223 individuals who contributed to the self-care of individuals with colostomy, ileostomy and urostomy, who applied for outpatient control.

#### Instruments

As data collection tools, an 11-item "Information Form for the Caregiver of the Individual with Ostomy" and the 22-item "Caregiver Contribution to Self-care in Ostomy Patient Index" were used.

The Information Form for the Caregiver of the Individual with Ostomy consists of questions about the sociodemographic characteristics of the family and relatives who contribute to the care of the individual with a stoma.

The "Caregiver Contribution to Self-care in Ostomy Patient Index" scale, developed in English by Villa et al. (2019)<sup>7</sup>, consists of 22 items and 3 sub-dimensions. Scale items are evaluated with a 5-point Likert-type. The first sub-dimension is "Caregiver Contribution to Self-care Maintenance", consisting of 9 items. The second sub-dimension is "Caregiver Contribution to Self-care Monitoring", consisting of 8 items, and the third sub-dimension is "Caregiver Contribution to Selfcare Management", consisting of 5 items. The 18<sup>th</sup> item of the scale, which evaluates the state of experiencing complications, has a low factor load and was accepted as an add-on. The highest 110 points are obtained from the scale, and it is stated that as the total score from the scale increases, self-care also increases<sup>7</sup>.

#### **Study Procedures**

The study sample consisted of individuals over the age of 18 years, who supported the care of the individual with a stoma (colostomy, ileostomy, or urostomy), who spoke, read and wrote in Turkish, did not have a cognitive problem that prevented them from expressing themselves, did not have a serious psychiatric diagnosis, and gave written consent to participate in the study. The data were collected by the researcher by face-to-face interview method, giving each individual approximately 30 minutes.

#### Ethics

In order to adapt the scale to Turkish, permission was obtained from the authors via e-mail<sup>7</sup>. Study procedures were reviewed and approved by the Non-interventional Clinical Research Ethics Committee of Tekirdağ Namık Kemal University Faculty of Medicine on August 27, 2020, with the decision number of 2020.195.08.04. Moreover, study procedures were reviewed and approved by the two public hospitals. The procedures used in this study adhere to the tenets of the Declaration of Helsinki, in accordance with good clinical practice. The study was carried out on a voluntary basis. Written and verbal consent was obtained from individuals who agreed to participate in the study. This study is registered in the clinical trial database with protocol number (NCT06269276).

### **Statistical Analysis**

Data were analyzed using lavaan Project and R Project package programs. Descriptive statistical methods (mean, standard deviation, frequency, and percentage) were used to analyze sociodemographic characteristics of the participants. The Shapiro-Wilk test was used for normality tests. According to the findings examined, the paired samples t-test from dependent 2 group comparison tests was used for the scores that were in accordance with the normal distribution, and the Pearson correlation test was used to determine the direction and degree of the relationship between the two scores. The Wilcoxon Signed-Rank test, which is one of the two dependent group comparison tests, and the Spearman correlation test were used to determine the direction and degree of the relationship between the two scores for the scores that did not conform to the normal distribution. Validity and reliability methods were used in the analysis phase. The margin of error was 5% and the significance was evaluated as  $p < 0.05^{10,11}$ .

## **Validity Analysis**

In the validity analysis of the scale, language and content analysis and confirmatory factor analysis (CFA) were used. In order to ensure language and content validity, the scale was first translated from English to Turkish and from Turkish to English by two independent linguists, and a common translation text was created<sup>12</sup>. The Content Validity Index (CVI) was used to examine and compare the compatibility of the translated text with the original study, and 11 expert opinions were obtained. In this method, each item is scored as "1-Not Relevant", "2-But Need Some Revision", "3-Relevant, But Needs Minor Revision" and "4-Very Relevant". The CVI is considered sufficient if at least 80% of the scale items are scored as 3 or 4 and the CVI value is above 0.8013. The scale, which was organized with expert opinions, was applied as a pilot study to a group of 10 people who contributed to the care of the individual with a stoma, and the scale was given its final shape. Data from this group were not included in the analyses13-15. In this study, CFA was applied to test the validity of a previously developed scale in different languages and samples. The Diagonal Weighted Least Squares technique was preferred since the data were

Likert-type in the estimation phase of  $CFA^{9,16}$ . The fit indexes obtained as a result of the analysis was at the desired level and the factor loads of the items were above 0.30 according to the path diagram. In addition, the t-values of the items are considered statistically significant at the 0.05 level if they are above 1.96 and at the 0.01 level if they are above  $2.56^{9,12,16-19}$ .

## **Reliability Analysis**

In the reliability analysis of the scale, item analysis and internal consistency and test-retest reliability were used. The Cronbach's alpha reliability coefficient and item-total score reliability, which measure the relationship between each independent item in the measurement tool and the other items and the whole scale, were used. Accordingly, the Cronbach's alpha coefficient 0.40-0.60 is reliable at a lowly level; a range of 0.60-0.80 indicates quite reliability, and a range of 0.80-1.00 indicates high reliability. In item-total score reliability, a correlation coefficient over 0.30 indicates the reliability of the item<sup>9,20</sup>. For test-retest reliability, the scale was repeated with 70 individuals who contributed to the care of the individual with a stoma at a 2-week interval, and the scale forms were matched after the application. The Pearson and Spearman correlation coefficients (r-value) are calculated in the testretest method. The r-value indicating the degree of reliability takes a value between -1 and +1 and must be at least 0.70 for reliability to be accepted9.

# RESULTS

Among the individuals participating in the study, 52% (n=116) were between the ages of 45 and 59 years; 64.6% (n=144) were female; 74% (n=165) were married, 36.3% (n=81) were middle school graduates, 62.3% (n=139) were not working, and 77.6% (n=173) were living with an individual with a stoma; 65% (n=145) of stomas belonged to individual's spouse and 42.2% (n=94) supported the care of the individual with stoma for 1-5 months; and 79.8% (n=178) received ostomy care training. In addition, 53.8% (n=120) of individuals with stoma had colostomy and the reason for ostomy opening in 70.9% (n=158) was cancer (Table 1).

In the validity analysis, the CVI value of the scale was found to be 0.99 in line with the expert opinions. As a result of CFA,  $\chi^2$ /sd=3.349 values were between 2 and 5 and goodness of fit index (GFI), Tucker-Lewis Index (TLI), comparison of model fit indices (CFI), adjusted goodness of fit index (AGFI) values were above 0.900 (Table 2). All items were included in 3 subdimensions with statistical significance and the 18<sup>th</sup> item was accepted as an add-on as it was in the original version of the scale (Figure 1, Table 3).

According to the reliability analysis statistics, the Cronbach's alpha coefficients were 0.890 for the overall scale, 0.867

for the "Caregiver Contribution to Self-care Maintenance" sub-dimension, 0.921 for the "Caregiver Contribution to Self-care Monitoring" sub-dimension, and 0.458 for the "Caregiver Contribution to Self-care Management" subdimension, respectively. As a result of the reliability analysis, the item correlation value of the 18th item was negative, so it was excluded from the analysis and the results in Table 4 were obtained by performing the reliability analysis again. According to the findings, all corrected item correlation values of the sub-dimensions were found to be positive. In addition, it was observed that there was no significant increase in the reliability coefficients when the item was deleted in the sub-dimensions of the Caregiver Contribution to Self-care in Ostomy Patient Index. According to the findings obtained in the final analysis stage, all questions were included in the analysis, as in the original version of the Caregiver Contribution to Selfcare in Ostomy Patient Index. With the test-retest method, the Pearson and Spearman correlation coefficient (r-value) was found to be between 0.973 and 0.987 for the sub-dimensions of the scale and 0.983 for the whole scale (Table 5).

#### DISCUSSION

In this study, the validity and reliability of a scale that evaluates the contribution of families and relatives to the self-care of individuals with a stoma in the Turkish language and Turkish society were examined. The sub-dimensions of the scale in its original form were prepared on the basis of Riegel et al. (2012)<sup>21</sup> "Middle-range Theory of Self-care of Chronic Illness". In the scale that evaluates the contributions of the families and relatives of individuals with a stoma, the first part of the scale, "Self-care Maintenance" is about daily routine behaviors; the second part "Self-care Monitoring" is about recognizing the stoma and its surroundings; and the third part, "Self-care Management", deals with recognizing problems and intervening behaviors<sup>7</sup>.

The back-translation method was used in the language adaptation of the scale and a common translation text was created. The CVI value of 0.99 in this study showed that language and content validity were appropriate<sup>13</sup>. Also, construct validity of the scale was tested using CFA. In this study, fit indices ( $\chi^2$ /sd=3.349 value below 5 and GFI, TLI, CFI and AGFI criteria above 0.900) showed acceptable fit. The factor loads of the items were found to be above 0.30 and their t-values above 2.56, at the level of 0.01, which was statistically significant. These results found that the items were correctly included in the original scale dimensions and were collected in 3 sub-dimensions<sup>9,12,16,19-20</sup>.

In this study, Cronbach's alpha reliability coefficient was found to be 0.890 in the overall scale and in the range of 0.458-0.921 in the sub-dimensions of the scale. The overall scale was

Table 1. Sociodemographic characteristics of families and       relatives contributing to the care of individuals with stoma							
Variables	n	0/0					
Age (years)							
18-29	11	4.9					
30-44	40	17.9					
45-59	116	52.0					
60+	56	25.1					
Gender							
Female	144	64.6					
Male	79	35.4					
Marital status							
Single	58	26.0					
Married	165	74.0					
Education level							
Literate	15	6.7					
Primary school	77	34.5					
Middle school	81	36.3					
High school	34	15.2					
University	16	7.1					
Profession							
Working	84	37.7					
Not working	139	62.3					
The state of living with an individual w	/ho has a s	stoma					
Yes	173	77.6					
No	50	22.4					
Degree of closeness with the individua	l with the	stoma					
Spouse	145	65.0					
Child	60	26.9					
Other	18	8.1					
Stoma type of individual with stoma							
Colostomy	120	53.8					
lleostomy	69	30.9					
Urostomy	34	15.2					
Cause of ostomy opening							
Cancer	158	70.9					
Obstruction	43	19.3					
Trauma	18	8.1					
Other	4	1.8					
Time to support the self-care of the individual with stoma							
1-5 months	94	42.2					
6-11 months	83	37.2					
1-3 years	19	8.5					
3-5 years	22	9.9					
5 vears+	5	2.2					
Status of receiving ostomy care training	a before a	lischarge					
Yes 178 79.8							
No	45	20.2					
	тJ	20.2					

Table 2. Fit indices obtained from confirmatory factor analysis for the Caregiver Contribution to Self-care in Ostomy Patient Index					
Indices	Perfect fit	Acceptable fit	Index		
$\chi^2$ /sd (chi-square goodness of fit)	<3	<5	3.349		
CFI	0.97≤ <b>CFI</b> ≤1	0.90≤ <b>CFI</b> ≤0.96	0.921		
GFI	0.95≤ <b>GFI</b> ≤1	0.90≤ <b>GFI</b> ≤0.96	0.934		
AGFI	0.95≤ <b>AGFI</b> ≤1	0.90≤ <b>AGFI</b> ≤0.96	0.918		
TLI	0.95≤ <b>TLI</b> ≤1	0.90≤ <b>TLI</b> ≤0.96	0.911		

CFI: Comparative fit index, GFI: Goodness of fit index, AGFI: Adjusted goodness of fit index, TLI: Tucker-Lewis index



Figure 1. Caregiver Contribution to Self-care in Ostomy Patient Index confirmatory factor analysis path diagram

Table 3. Caregiver Contribution to Self-care in Ostomy Patient Index confirmatory factor analysis statistics						
Sub-dimension	Item	Estimate	Standard error	t-value	р	
	Item 1	1.000	-	-	-	
	Item 2	0.973	0.075	13.018	<0.001	
	Item 3	1.273	0.090	14.197	<0.001	
	Item 4	1.247	0.087	14.315	<0.001	
Caregiver contribution to self-care	Item 5	1.030	0.075	13.760	<0.001	
	Item 6	1.314	0.094	13.952	<0.001	
	Item 7	1.023	0.075	13.602	<0.001	
	Item 8	1.120	0.079	14.188	<0.001	
	Item 9	0.826	0.069	11.903	<0.001	
	Item 10	1.000	-	-	-	
	Item 11	0.931	0.051	18.202	<0.001	
	Item 12	0.797	0.046	17.420	<0.001	
Caregiver contribution to self-care	Item 13	0.825	0.047	17.586	<0.001	
monitoring	Item 14	0.853	0.049	17.503	<0.001	
	Item 15	0.888	0.051	17.305	<0.001	
	Item 16	0.735	0.045	16.341	<0.001	
	Item 17	1.026	0.057	18.049	<0.001	
	Item 19	1.000	-	-	-	
Caregiver contribution to self-care	Item 20	0.622	0.091	6.805	<0.001	
management	Item 21	1.115	0.124	9.003	<0.001	
	Item 22	1.584	0.158	10.054	<0.001	

Table 4. Caregiver Contribution to Self-care in Ostomy Patient Index item analysis and internal consistency results							
Sub-dimension	ltem	Median	Corrected item-total correlations	Cronbach's alpha if item deleted	Cronbach's alpha		
	Item 1	4.000	0.426	0.868			
	ltem 2	4.000	0.466	0.865			
	Item 3	4.000	0.723	0.841			
Caregiver contribution	ltem 4	4.000	0.729	0.841			
to self-care	Item 5	4.000	0.648	0.849	0.867		
maintenance	ltem 6	3.000	0.666	0.847			
	ltem 7	4.000	0.630	0.851			
	ltem 8	4.000	0.679	0.846			
	ltem 9	4.000	0.454	0.867			
	ltem 10	4.000	0.810	0.904			
	ltem 11	4.000	0.766	0.908			
	ltem 12	4.000	0.724	0.911			
Caregiver contribution	Item 13	4.000	0.718	0.912	0.921		
to self-care monitoring	ltem 14	4.000	0.752	0.909			
	ltem 15	4.000	0.701	0.913			
	ltem 16	4.000	0.618	0.920			
	ltem 17	4.000	0.793	0.906			
Caregiver contribution to self-care management	ltem 19	4.000	0.292	0.356			
	Item 20	4.000	0.206	0.437	0.458		
	ltem 21	4.000	0.345	0.302			
	Item 22	4.000	0.206	0.444	7		
Caregiver Contribution t	0.890						

Table 5. Test-retest results of Caregiver Contribution to Self-care in Ostomy Patient Index sub-dimensions								
	Caregiver to self-ca	contribution re maintenance	ntribution Caregiver contribution to self-care monitoring		Caregiver contribution to self-care management		Caregiver contribution to self-care in ostomy patient index	
	r	р	r	р	r	р	r	р
Test-retest	0.987	<0.001 <sup>P</sup>	0.976	<0.001 <sup>s</sup>	0.973	< 0.001 <sup>s</sup>	0.983	< 0.001 <sup>s</sup>
<sup>P</sup> · Pearson correlation coefficient <sup>S</sup> · Spearman correlation coefficient								

r: Pearson correlation coefficient, 3: Spearman correlation coefficient

highly reliable. In addition, in the item-total score analysis, it was concluded that the correlation coefficient of all items was above 0.30 and there would be no increase in the Cronbach's alpha value when the item was deleted. As a result of the analysis, the Pearson and Spearman correlation coefficients of the sub-dimensions were found to be between 0.973 and 0.987. Accordingly, the sub-dimensions of the scale were highly reliable and did not change over time<sup>9,17</sup>.

The similarities of the original version of the scale with our study are that the scale items consist of 3 sub-dimensions, the CVI is 0.93 and the Cronbach's alpha is 0.972 in the internal consistency analysis.

## **Study Limitations**

The most important limitation of our study is that it was conducted with families and relatives who contributed to the care of individuals with stoma in two public hospitals in Turkey. However, the validity and reliability of the scale in Turkish has been ensured and it is recommended to be used in other studies in Turkish society.

# CONCLUSION

Individuals with stoma often need the support of their relatives in order to maintain their self-care. There is no valid and reliable scale in Turkish language to evaluate the relatives who participate in the care of individuals with a stoma and contribute to their self-care. As a result of the research, it has been determined that the "Caregiver Contribution to Self-care in Ostomy Patient Index" is a valid and reliable scale for Turkish society in the Turkish language. This scale can be used as a guide in the evaluation of families and relatives who contribute to the self-care of individuals with a stoma in Turkish society.

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#### Ethics

**Ethics Committee Approval:** Study procedures were reviewed and approved by the Non-interventional Clinical Research Ethics Committee of Tekirdağ Namık Kemal University Faculty of Medicine on August 27, 2020, with the decision number of 2020.195.08.04.

**Informed Consent:** Written and verbal consent was obtained from individuals who agreed to participate in the study.

#### **Authorship Contributions**

Design: T.Y., A.M., D.E., Ç.A., E.Ö., Y.D., U.C., S.Ö.G., Data Collection or Processing: T.Y., A.M., D.E., Ç.A., E.Ö., Y.D., U.C., S.Ö.G., Analysis or Interpretation: T.Y., A.M., D.E., Ç.A., E.Ö., Y.D., U.C., S.Ö.G., Literature Search: T.Y., Ç.A., Writing: T.Y., Ç.A.

**Conflict of Interest:** No conflict of interest was declared by the authors.

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